

sang at the Lincoln Memorial, the barriers for Black people began to fall, but it was another 50 years after her performance before the barriers for people with disabilities really started to come down. The Americans with Disabilities Act (the ADA), signed by President George Bush, assured the 49 million people with disabilities of their rights.

The focus of the film transitions to individuals with disabilities. James DePreist, nephew of Marian Anderson, faced many racial barriers along his road to success as a prominent conductor, and, when he contracted polio, he began to notice the physical barriers that denied him access within our society. DePreist claims the ADA gives individuals who are disabled the opportunity to "battle" the prejudices and become "equated" with the general public.

Kathy Martinez, a blind woman, reflects on her experiences. As a child she was faced with low expectations by those around her. She graduated from high school and went to college in Berkeley, CA. While at Berkeley, she learned how to live with her disability. Not only that, she encountered protests that were raised by disabled people against discrimination and the refusal of the Carter Administration to enforce the Federal Rehabilitation Act, Section 504, which states that "when receiving Federal money, facilities must be accessible to people with disabilities." After three years of protests, Kathy decided to become involved, but feared that she would be kicked out of school and had to conceal her involvement. On April 28, 1977, the Carter Administration backed down to protestors and promulgated the regulations. From that point on, Kathy set out to help individuals with all types of disabilities to become more independent within society. Today, because of the ADA, Kathy is guaranteed that her employer will provide her with the equipment necessary to do her job, and that all facilities will be accessible.

Hughey Walker and Lena Myers are two other people highlighted in this film. Hughey is an individual who grew up in a very racist society in the South. Blacks were banned from working in certain factories and were confronted with signs that said "white entrance only." Hughey joined the Army in 1966. When he returned home more than a year later disabled from a wound, the racist signs were slowly beginning to come down, but inaccessibility for disabled people was still predominant. When his daughter was in elementary school, he had to sue the school to make it accessible for him to visit her classroom. Lena was also faced with physical and attitudinal barriers throughout her life. After her accident, her family members saw her as incapable of being independent, and prospective employers would not even consider hiring her. She ended up starting her own catering business and became quite successful.

T.J. Monroe is the last individual presented in this film. He spent most of his life in an institution. Once released, he became an advocate and worked with people with disabilities nationwide. President Bill Clinton appointed him to the President's Committee on Mental Retardation. Monroe conducts workshops for people with disabilities that help them to become more confident and independent. Their family members attend, too, to support the process. The bottom line of T.J.'s seminar is to assure disabled individuals that they are equal and to encourage them not to be afraid to attain goals and achievements that others take for granted, such as marriage, independent living, and a job.

*My Country* is an exceptional film. It is amazing that disabled people have had to exert so much energy and to fight so hard for the basic rights that all people have. This film demonstrates that societal attitudes may be more disabling than physical impairments. The film reinforces the notion that the abilities of people who are disabled should not be underestimated. People are only disabled by societal stigma and society's unwillingness to include individuals with physical differences.

### **Minutes of the Federal Interagency Subcommittee on Disability Statistics**

The Federal Interagency Subcommittee on Disability Statistics is the only federal group concentrating on disability statistics (including methodology questions) which is completely accessible to interested

disability studies scholars. Because of their public openness and because of the importance of what they discuss, Disability Studies Quarterly carries edited versions of their email minutes. Usually only information reported elsewhere in the Quarterly or future agendas of meetings already held (they meet monthly) are edited out. However, since the Quarterly has fallen behind in its publication schedule and there are several months of minutes available, the Editor was more stringent in his editing. Complete monthly minutes can be obtained on a regular basis via email from Carolyn Ward at Conwal Incorporated, 6858 Old Dominion Drive, Suite 200, McLean, VA 22101, 703-448-2300 (V), 703-448-3079 (TTY), 703-448-3087 (FAX), CWardCon@AOL.Com (EMAIL).

ALL EDITING WAS DONE BY THE EDITOR OF DISABILITY STUDIES QUARTERLY USING THE EMAIL VERSION OF THEIR MINUTES.

#### REPORT OF JULY 8, 1998, MEETING:

1. Dr. Don Lollar (email: dcl5@cdc.gov) and Dr. Michael Marge (email: marge@sued.syr.edu) provided an update on "Healthy People with Disabilities, 2010." Dr. Marge reported on the conference, "Healthy People 2010 Disability Objectives: Private Sector and Consumer Perspectives" held April 19-20. The conference was co-sponsored by the American Disability Prevention and Wellness Association (ADPWA), the Centers for Disease Control (CDC), the Agency for Health Care Policy and Research (AHCPR), the National Association of Rehabilitation Research and Training Centers (NARRTC), the National Council on Disability (NCD), Unum Insurance, the Association of State and Territorial Health Officials (ASTHO), the Spina Bifida Association and Paralyzed Veterans of America (PVA).

The conference provided a forum for provider and consumer input on the 2010 draft disability objectives. Sixty-five people were invited to attend; they were asked to review the draft 2010 objectives prior to the meeting. The draft disability objectives under consideration included: 1) those planned for a chapter focused specifically on people with disabilities (an historic event in that this is the first time such a targeted chapter will appear in this public health document) and those for use in other chapters. The proposed objectives covered health promotion, disease prevention, health care access, and social and personal participation.

Dr. Marge pointed out that many developmental objectives were discussed during the course of the conference. Measurable disability objectives are currently lacking.

Dr. Lollar discussed several issues related to 2010 Disability Objectives: 1) A chapter was developed on Mental and Physical Impairment and Disability. A recommendation has been forwarded to move mental health into its own chapter, and to include birth defects in a chapter on maternal and child health. ODH has submitted 55 disability objectives for placement in other chapters. It is possible that such recommendations will come under a subsection on people with disabilities. Developmental sub objectives may also be included.

Dr. Lollar pointed out several key 2010 proposed disability objectives. Objective #1 states that, "By the year 2003, all data sets used for Healthy People 2010 will include a core set of items to identify people with disabilities." He also discussed Objective #10, "All patient encounter forms will include a summary of Activity Limitations and Participation, using World Health Organization International Classification of Impairments, Disabilities and Handicaps-2 codes for all individuals receiving health care."

Dr. Hendershot asked Dr. Lollar to name the data sets that should include a core set of items to identify people with disabilities. Dr. Lollar mentioned the National Health Interview Survey (NHIS), the Youth At Risk Behavioral Survey (YRBS), the National Health and Nutrition Examination Survey (NHANES), Continuing Survey of Food Intake by Individuals (CSF 2), The Medical Expenditure Panel Survey (MEPS), the National Crime Victim's Survey, and State Cancer Registries. Dr. Hendershot commented that standardization and additional questions are needed in these surveys. Dr. Lollar responded that he anticipated NCHS leadership on this.

Dr. Mitch LaPlante asked about future milestones. Dr. Lollar sees the 2010 disability objec-

tives as a means to promote an agenda that relates to data and services. Bob Williams of ASPE, Dr. Kate Seelman of NIDRR and Dr. Lollar will conduct a panel presentation at the American Public Health Association meeting in November on the 2010 Objectives. Additionally, the 2010 Draft Objectives are scheduled to appear in the Federal Register in September.

Dr. Marge suggested that it is important to get private industry involved in helping to improve people's health status. Perhaps private profit could be placed back into the community to benefit the public health.

Dr. Gray raised the issue of the measurement tool of participation. In response, Dr. Lollar discussed Objective #16, "Environmental factors will be rated as barriers to participation at home, work and the community by an equal proportion of people with and without disabilities." Dr. Gray also offered to work on the Medical Product Safety Chapter.

It was mentioned that HCFA, SSA and the Department of Veterans Affairs are interested in using codes related to function and limitation. Uniformity on this issue would be welcome. Disease diagnoses codes fail to reflect the needs of persons with disabilities.

Dr. Melia asked about use of ICIDH codes by allied health professionals. Dr. Lollar explained that the American Occupational Therapy Association, the American Physical Therapy Association and the American Psychological Association are strongly supportive of the ICIDH revision and that this classification system would be used in patient encounter forms.

2. Dr. Gerry Hendershot (email: geh2@cdc.gov), Terry DeMaio (email: theresa.j.demaio@ccmail.census.gov), Jim Esposito (email: j@bls.gov), Barbara Wilson (email: bwf3@cdc.gov) and Nancy Mathiowetz (email: nmathiw@survey.umd.edu) discussed "Research on Disability Survey Methodology." Dr. Hendershot explained that this work is the outgrowth of a comment made by Howard Moses at the February Interagency Committee on Disability Research (ICDR) meeting. Moses spoke of the need to develop reliable, valid, concise data collection systems. At the May ICDR meeting, Dr. Hendershot was asked to outline a research program on disability surveys; his presentation was well-received. Dr. Katherine Seelman, ICDR Chair, then charged the ISDS to come up with an action plan for the upcoming August ICDR meeting.

DeMaio, Esposito, Wilson, and Mathiowetz were asked to discuss what their organizations do and how their work relates to disability.

Terry DeMaio is in the Statistics Research Division in the Center for Survey Methods Research at the Bureau of the Census, where the Cognitive Laboratory, which tests Census 2000 questions and other Census survey questions, is housed. She conducts research on demographic, interviewer-driven, and self-administered questions. Her division tapes interviews in the field and conducts split panel tests to see which versions of questions work best. Her office also has responsibility for debriefing questions, and analyzing how people interpret certain terms used in survey questionnaires.

DeMaio participated in the Interagency Committee that worked on the disability questions for Census 2000. She conducted cognitive interviews on the two sets of disability questions (one from the Administration; the other from the Bureau of the Census), and developed and improved the set of questions that was used in the Census 2000 dress rehearsal.

Jim Esposito is a social psychologist and survey methodologist who worked on the Current Population Survey and displaced worker supplement. His expertise is in questionnaire design and evaluation. He pretests draft surveys for reliability and accuracy. He also conducts quality assessments of surveys in the field. Esposito is involved with respondent/interviewer debriefing, assessing concepts, and behavior coding. All the work done is collaborative. Survey design specialists rely on subject survey specialists. Esposito pointed out that clear definitions or objectives are imperative in survey design.

BLS has collaborated with Census Bureau staff on disability issues; the agency has not traditionally been a lead agency in disability survey research.

Barbara Wilson of NCHS spoke of her work on cognitive testing for health questionnaires

and modules. She determines problems with questions and terminology. She analyzes whether respondent experience fits into the concept of the questions posed and tries to take into account problems that may be caused by embarrassment or sensitivity. Sometimes, she is called upon to break down questions to simplify them. This must often take place within a context where the number of questions must be pared down. Her work involves developing a core set of items that are valid, reliable and short.

Wilson will be laboratory testing three alternative sets of questions from Don Lollar and Vince Campbell for use in the Behavior Risk Factors Surveillance Surveys (BRFSS). NCHS is exploring whether telephone surveys would have a standardized set of questions that would also appear on a self-administered survey. There may be problems in using the same questions administered in different ways.

Nancy Mathiowetz of the Joint Program in Survey Methodology, an interdisciplinary effort administered by the University of Maryland, the University of Michigan and Westat trains survey methodologists for the Federal government and considers the issue of non-response to surveys. The JPSM mission is to work on research activities affecting multiple agencies.

Mathiowetz explained that the measurement of disability poses enormous conceptual and implementation challenges. Perceptual differences regarding disability abound. It is difficult to devise methods on how to report disability. A programmatic approach is needed.

Jim Esposito explained that BLS has an interest in disability due to President Clinton's March 13 Executive Order establishing a National Task Force on Employment of People with Disabilities and its requirements related to data gathering on employment issues. The new paradigm of disability and the ICIDH multidimensional approach covering Impairment (body systems), Activity Limitations (functional issues) and Participation Restrictions (social dimensions) raise complications. Can federal agencies ask respondents to make these kind of distinctions in surveys?

Demaio explained that the change in the definition of what disability is raises important survey research methodology questions. 1) What are the objectives? 2) What are you trying to measure? 3) Can respondents provide that information? Exploratory research is needed with respondents to identify their impressions via focus groups and one-on-one unstructured interviews. Information must be sought from both disabled and non-disabled populations.

Esposito spoke of the needs of survey evaluators. It is most important to have a single sponsor with accountability and authority to define the key concepts or ideas in a questionnaire. It is not possible to have multiple definitions; problems exist with multiple sponsors. Clear questionnaire objectives must be defined.

Esposito discussed the old paradigm of disability which encompasses "the medical model," and is extremely complex. The new paradigm of disability adds Environmental components and Participation, and deals with those interactions as ADA concerns. This model increases complexity. Those involved in developing questionnaires need information gathered from major literature searches, data on Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). Additionally, they need one set of definitions to use.

Mathiowetz pointed out that it is the job of survey methodology to help translate substantive information into measurable concepts. One must move from the concept to a set of questions that operationalize the concept. Questions must be put in language that has the same meaning to all people and must be tested and evaluated for validity and reliability. In essence, researchers must reach agreement about the concept that needs to be measured and how it will be operationalized. Then, testing must take place.

Dr. David Gray spoke of major threads that need to be taken into account in disability survey research methodology. He stated that: 1) general agreement exists on the concept of disability. Dr. Gray cited the 1997 IOM report, *Enabling America*, and its focus on the integration of Environmental factors as well as on Impairment, Activity and Participation. 2) it is important to look at the population of people affected which includes, people with impairments, spouses, relatives, and care

providers. Lots of work is taking place in federal databases and at WHO, but we need to ensure that it is helpful in measurement, i.e., that accurate measures are developed.

Dr. Paul Placek asked about the half dozen Census questions on disability that were not laboratory tested, but were used in the dress rehearsal. He wanted to know what kind of assessment they would receive. According to Terry Demaio, Jack McNeil of the Bureau of the Census will evaluate the dress rehearsal data. He will examine the data for item non-response, patterns and correlations. It is possible that this data are available now.

Dr. Lollar spoke of three sets of questions that he and Vince Campbell submitted to the Bureau of the Census. These alternatives include NHIS redesigned questions, and materials from CIHI and European groups. Consideration of the purpose of the survey and who wants it are critical policy issues that need to be taken into account.

Dr. LaPlante raised the issue that the Census relies on test/retest reliability. So how do you test/retest reliability with disability, a dynamic state? Dr. Gray used the example of Social Security and optimal work conditions. Social policy comes into play with such an issue since we need to improve the Environmental context and consider Assistive Technology use when discussing work.

#### ANNOUNCEMENTS

Regarding the recent report from the "International Symposium on Job Retention and Return to Work for Workers with Disabilities," the final report of the first phase of the research project is not yet ready. The only reports available thus far are those which were prepared prior to the Symposium which includes a report on the cross-cutting issues and an individual country report from each of the 8 countries in the study. If there are questions, the head of the Research Team for the project is: Patricia Thornton, Research Fellow, University of York, Heslington, York YO1 5DD, UNITED KINGDOM, Tel: 44 1904 433608, Fax: 44 1904 433618, E-mail: <pat3@york.ac.uk>.

The Final Report from the International Leadership Forum for Women with Disabilities held last June in Bethesda, MD is ready and single copies can be obtained from: Rehabilitation International, 212 420-1500, <rehabintl.aol.com>.

#### REPORT OF AUGUST 12, 1998, MEETING:

(1) Gale Whiteneck (email: gale@craig-hospital.org) and C.A. Brooks presented a research update on measuring participation and environment. This CDC sponsored research, funded through the Office of Disability and Health 731 Grants, is using a BRFSS based survey tool and the CHART Short Form (a participation tool) to assist in the development of environmental measures.

The project's strategy involves reviewing conceptualization of environmental factors. Four panels, covering mobility, personal assistance, communication and learning are being convened to test items and metrics.

The determinants of participation have been outlined and include both internal and external factors. Internal factors can either be related to the disability or not related to the disability. Internal factors related to the disability include 1) impairments; 2) disabilities and compensatory abilities. Internal factors not related to the disability include demographic characteristics and life experience characteristics. External factors that must be taken into account consist of environmental factors influencing participation.

Under the project's aegis, environmental factors have been defined as all characteristics, external to an individual with an impairment or disability, that influence that individual's performance as a member of society. Simply put, environmental factors are the external influences on participation.

The project has turned to various complementary conceptual schemes to list environmental factors. These conceptual schemes include: categories developed by Patrick Fougeyrollas, ICIDH-2 chapters, levels of analysis, characteristics and domains. Environmental elements encompass political-economic, socio-cultural and natural factors.

Environmental categories cover 1) support and attitudes of family and friends; 2) income, job and income security; 3) governmental and other services; 4) physical environment and accessibility.

ity; 5) aids, devices and technology; 6) equal opportunity and political orientations.

The six ICIDH-2 environmental chapters include: 1) products tools and consumables; 2) personal support and assistance; 3) social, economic and political institutions; 4) sociocultural structures, norms and roles; 5) the human-made physical environment and 6) the natural environment.

Levels of analysis of the environment may take place on a micro, meso or macro scale. A micro level of analysis focuses on the immediate personal environment. The meso level examines the community environment, while the macro level covers the broad societal environment. Characteristics of the environment include: accessibility, accommodation, resource availability, social support and equality.

Accessibility responds to the question, can you get where you want to go? It is defined in terms of physical access and includes architectural barriers and accessibility of transportation.

Accommodation addresses the question, can you do what you want to do? It is defined in terms of equipment, services and modification of tasks which facilitate full participation. It includes home, work, school and other business and community settings.

Resource availability answers the question, are your special needs met? It is defined in terms of the availability and the provision of the services and resources made necessary by disability. It includes medical care, personal assistant services, and income security.

Social support responds to the question, are you accepted by those around you? It is defined in terms of the attitudes and prejudices of others. It includes family and friends, employers and teachers, neighbors and peers and other community members.

Equality addresses the question, are you treated equally with others? It is defined in terms of the degree to which policies and regulations insure equality of opportunity for people with disabilities. It includes discrimination and financial disincentives, health care management and rationing, legislative mandates.

Another set of elements in the conceptual framework for listing environmental factors include the practical domains. They consist of physical, attitudinal and policy barriers.

The project is using metrics for measuring environmental factors. It is employing an influence scale which covers whether an environmental factor represents 1) a big barrier; 2) a little barrier; 3) no impact; 4) a little help; 5) big help. A frequency scale will examine impact on a 1) daily; 2) weekly; 3) monthly; 4) less than monthly; or 5) never basis.

Environmental items that will come under consideration include transportation, education, design and layout (of home, school/work, the community), health care, equipment, technology, personal assistance (in the home, work/school, community), the natural environment, surroundings, and access to usable information. Other items that will be scrutinized are people's attitudes (in home, work/school and community settings), support and encouragement (in home, work/school and community settings), discrimination, programs/services, business policies, education/employment programs, government programs, opportunities and avoidance of barriers.

Test results will be plotted. The preference exists to use the frequency scale over the influence scale. In fact, it is better differentiated than its counterpart scale. The project seeks to moderate the relationship between the influence and frequency scales.

The next steps involve recommending use of the frequency scale. The project will add a severity follow-up. It will seek reaction from the panels and conduct more extensive tests. It plans to add measures to the BRFSS in Colorado for 1999.

(2) Becky Hayward (email: bhayward@rti.org) and Harold Kay (email: harold\_kay@ed.gov), reported on "RSA's Longitudinal Study of the Vocational Rehabilitation (VR Services Program: Design, Status and Preliminary Findings). This research covers 8,500 cases, and is the most comprehensive database on VR services received. This public use database follows participants for 3 years examining the impact of vocational rehabilitation on that population. The final report is due in the Year 2000. The study will also extend follow-up for an additional two years. Results will most likely feed into the next Reauthorization of the Rehabilitation Act.

Demographic information, and data on disability, functional level and work histories of participants are being collected, providing a good description of individuals. The study is identifying variables such as environmental information, economic information, office information, staff information, organizational variables such as the degree of counselor autonomy, and educational levels of counselors that relate to outcomes.

Presently RSA 911 data tracks everyone served. Yet this client level data can only account for 1/3 of the variance on outcomes. Hopefully with the Longitudinal Study, there will be better outcomes. This huge database will be useful fodder for future doctoral dissertations.

RSA wants to share this information with researchers in the form of a public use database, and seeks to place data in a setting where it will be actively researched. The contractor will only be able to mine a fraction of what is available and RSA seeks widespread use of this database in the future.

(3) Leeanne Carrothers (email: lcarroth@westernu.edu) and Gretchen Swanson (email: swanco\_inc.@msn.com) presented an alpha level progress report on their ICIDH-2 Based Assessment of Functional Risk.

The current revision of the ICIDH allows data systems to capture person and environmental conditions that effect the need for and outcome of care. Its universal coding systems allow quantification over clinical and administrative levels. Swanson and Carrothers have proposed a way to consider the implications of a functional approach using ICIDH-2 data at different points of the health system.

The presenters provided an overview of the project. They outlined the perceived need for this work, its history and methods, assumptions and hypotheses, alpha level implementation criteria, alpha level findings, potential significance and time line.

An examination of a functional approach using ICIDH-2 data is justifiable as health plans and systems are becoming increasingly accountable for person (as opposed to diagnosis) based care. Person-based care and risk adjustment requires specifying status and need in a systematic and efficient manner. Functional data is frequently cited as one of the best ways to categorize and monitor quality and efficiencies of care. The perceived need for (and appreciation of) a person-based system varies across health care delivery systems. So, criteria that simplify collection and analysis of functional data would seem to be a reasonable "first-step" towards a system of person-based care.

In November 1997, Western University convened a Consensus Panel which identified that integration of functional data could potentially reduce risk. Such an effort would require federal regulation and support.

It would be necessary to specify payor-based criteria for the use of functional data within and across the health care system. Additionally, it would be important to define health perception in terms of the ICIDH-2 functional taxonomy and to model interdisciplinary orientation to functional risk assessment.

The project's conceptual framework and design elements/criteria were presented to the original members of the consensus panel for critique. Student orientation to functional classification was implemented in April 1998.

Project assumptions included three important concepts. First, the current US health care system can accurately be described as an acute care model. Secondly, the functional model may be a meaningful alternative. Finally, students in the health professions are likely candidates to implement functional classification.

Three hypotheses would be tested. The first would examine causal elements, that functional data used within an acute care model creates system inefficiencies. Then, impact would be investigated. The hypothesis would be that a functional approach to data and the creation of a universal data set would streamline operations, and reduce oversight and other administrative costs. Additionally, an action hypothesis would be examined, that a functional model would change the process of health care delivery.

The implementation criteria for the study covered six major issues: 1) all functional and

health perception tools would be cross-walked to ICIDH-2; 2) national and ICIDH-2 data sets would be used to compile functional profiles, readjust risk, and categorize a given target population; 3) existing clinical standards of care would be evaluated using the functional profile assessment; 4) national quality review organizations would require a comparison of expected with actual performance by functional profiles; 5) quality of care report cards would be published using performance based on functional profile; 6) health professions and medical students would be educated in the functional model for clinical decision making.

The presenters shared the alpha level findings of the project. They discovered that an acute health care model is an accurate way to describe the current US health care system. Additionally, they learned that a functional model may be a significant alternative to the present system, with the following considerations: a functional model would allow prospective rather than retrospective review regarding utilization; a functional model would evaluate existing intervention processes; a functional model would allow forecasting of an outcome, not possible in an acute model. Additionally, they found that a functional approach to data would streamline operations and reduce oversight and other administrative costs only with wide consensus and federal regulation.

There were other alpha level findings. Swanson and Carrothers discovered that implementation criteria are appropriate for the conceptual framework, given the following conditions: they may need to be further specified for managed care; additional criterion ought to be added regarding patient education/satisfaction based on functional profiles; clinical standards based on functional care need to be added; some criteria need revision, as cross-walking is never a 1:1 process; criterion need to be refined for prediction of cost and outcomes.

They also found that students in health professions can shift perspective from an acute medical to a functional point of view. Further testing is warranted.

There is potential significance from these findings. Outcomes could include the creation of a universal translation system for existing functional data sets, criteria for a functional approach to delivery of services, and methods to transition from an acute model of care to a functional approach for health maintenance.

The presenters concluded with time line information:

June 1997: The WHO ICIDH-2 Beta Draft became available.

August 1997: North American Focus Groups were established.

November 1997: The Payor Consensus Panel was established.

January 1998: The Payor Consensus Panel report suggested an important relationship between functional data, a functional model, and health systems needs.

March 1998: Western University receives Intramural Grant.

April 1998: Orientation to functional model provided to Western University PT Students.

May-June 1998: Informal discussions with payor panel take place.

July 1998: Alpha Criterion is completed as a precursor to the recommended functional model. Responses are collected from expert payor panel to confirm needs and analyze criterion within their individual systems.

August 1998: Alpha Level Report given

The next steps involve:

August 1998: Payor Panel collaboration on alpha criteria testing.

September 1998: Prepare a proposal to validate a functional model within the existing health care system.

December 1998: Receive funding for functional systems model project.

## ANNOUNCEMENTS

Data on Charges based on Disability: The Equal Employment Opportunity Commission has recently added comprehensive administrative enforcement statistics to the EEOC Web site at <http://>



www.eeoc.gov. The Enforcement Statistics section includes the number of charges filed with EEOC, the statute under which the charges were filed, the basis of the alleged discrimination, and the monetary benefits paid to the individuals whose claims were resolved. The data will be updated in October.

NIDRR is developing a priority or priorities on research needs in Medical Rehabilitation Services and Outcome Measures. Your opinions are requested on research needs in those fields. Also, NIDRR may conduct a focus group on Outcome Measures. Your suggestions for literature to be distributed beforehand and suggested focus group participants would be helpful. Please contact David Keer if you wish to discuss these issues.

The 5th Annual North American Collaborating Center (NACC) meeting on the ICIDH will be held in Vail, Colorado at the Marriott Mountain Resort on October 5th, and 6th 1998. Representatives from the United States and Canada with expertise and interest in ICIDH will participate as well as WHO and other international collaborating center representatives.

There will be a meeting of Spanish language experts November 9-13, 1998 in Santander, Spain, for the purpose of completing the translation of the ICIDH-2 into Spanish. This is a followup to the Mexico city meeting for the same purpose. The meeting in Spain is hosted by Dr. Bazquez Barquero. For more information, contact Dr. Ustun at WHO (email: [ustun@who.ch](mailto:ustun@who.ch)).

#### REPORT OF SEPTEMBER 9, 1998, MEETING:

1. Rune Simeonsson ([rune\\_simeonsson@unc.edu](mailto:rune_simeonsson@unc.edu)) spoke on Students with Disabilities: A National Survey of School Environments. The purpose of the survey was to measure dimensions of school environments and participation of students with disabilities. A 4-page survey was sent to a random probability sample of 3000 special education teachers. Responses were received from 1200 teachers. The survey asked questions about the school as a physical environment including characteristics such as urban/rural, number of special education teachers, and number of students served. Other questions asked about school atmosphere or culture, including access and parental involvement. Teachers were asked to select one student and describe the nature of the student's impairment, how involved the student is in school activities, and to comment on the quality of life for that student. Results are organized into elements of participation: personal, cultural, social, economic, and civic. Results include demographics of students in special education, services provided, school size, quality of life, modal school environment, getting to school, and participation in school activities. A follow up study is planned of teachers expressing an interest in the study. A slide presentation with detailed findings is available from Rune Simeonsson.

2. David Gray ([dgray@ot-link.wustl.edu](mailto:dgray@ot-link.wustl.edu)) reported on progress on the Mobility Participation Survey (MPS) and the Environmental Barriers and Facilitators Listings. For each of five populations (spinal cord injury, cerebral palsy, multiple sclerosis, stroke, and polio), qualitative research activities included both individual interviews and focus groups numbering six to eight participants. Both types of activities were conducted with mobility limited individuals, significant others, and professionals who work with these populations. Four additional focus groups included designers, builders and architects; health professionals who work with adaptive equipment; unemployed persons receiving SSDI/SSI; and employed persons who received SSDI/SSI in the past.

Questions were designed to elicit information about what major life activities individuals with these mobility limitations participate in and what they see as environmental barriers and facilitators to their participation. Following the interviews, questions were reviewed and refined to be used in the focus groups. All sessions were audiotaped and transcribed. Focus group transcripts were then analyzed for categories of participation and environmental factors, using the constructs outlined in the proposed revision of the International Classification of Impairments, Disabilities, and Handicaps as set forth by the World Health Organization. From these data, two draft assessment tools were developed: the Mobility Participation Survey (MPS) and the Environmental Barriers and Facilitators Listing (EBFL). These two surveys are currently undergoing reliability and validity testing as part of the

CDC 731 project, "Mobility, Disabilities, Participation and Environment."

3. Harry E. Marshall (harry.marshall@mail.va.gov) Programs Manager, Rehabilitation Strategic Healthcare Group, Veterans Health Administration, reported on the VHA-sponsored conference: Outcomes to Measure Quality and Value in Disability Management, held August 26-28, 1998. The purpose of the conference was to provide the framework and parameters to develop a Disability Management Index.

Objectives of the conference were: (1) Identify the relative advantages and disadvantages of the WHO ICIDH-2 in providing a framework for establishing outcome tools to measure quality and value in disability management. (2) Identify the outcome domains relevant to veterans with disabilities that are important throughout VHA's continuum of care. (3) Recommend the outcome domains of interest to consumers, payers, and health care providers. (4) Identify assessment tools that would measure outcome domains while meeting psychometric standards of feasibility, simplicity, reliability, validity, low respondent burden, clinical utility, and risk adjustment. (5) While incorporating common disability management domains of value, explain the need for specific outcome measures in certain specialized programs/populations.

Included in the conference were 110 participants; 28 were from outside the VA. Domains of function as presented from ICIDH-2 were generally adopted in developments and deliberations. Each group processed and presented parallel activities. Employment and Community Support sub-group provided a slide presentation which is available from Harry Marshall.

The sponsoring organization, CARF Steering Committee's Recapitulation and Ontogenesis of the Conference was conducted on September 9 and included the following: (1) The ultimate goals were not reached. (2) Many measures currently exist specific to the services, e.g., PM&R, Audiology, Addiction, etc. (3) There is a need to develop participation measures which are global in scope. (4) VHA's intent to provide the SF36v on a census basis is a powerful opportunity for life quality assessment. (5) Population subgroups could be teased out or designed into this instrument, e.g., Vietnam, Gulf War, SCI, TBI, etc. (6) Each of the tracks should continue selecting instruments and seek consensus through designated leadership with additive members. (7) A consensus, for three track White Paper, should be developed.

## ANNOUNCEMENTS

Rune Simeonsson (rune\_simeonsson@unc.edu) announced that following the Fifth NACC Collaborating Center Meeting in Vail, there will be a follow up meeting on October 6 and 7, 1998 at the Imhoff Pavilion, The Children's Hospital Campus, 1825 Marion Street, Denver, CO. The focus of the meeting is: Strategies for Documentation of Participation of Children and Families in Early Intervention and Special Education.

Paul Placek announced that he and co-chair David Keer are working on adding new Envision sites, including NIH. As more sites are added, it may be necessary to change how the meeting is currently run. Anyone with suggestions should contact Paul Placek (pjp2@cdc.gov) or David Keer (David\_Keer@ed.gov).

Two disability sessions are included in the call for papers of the August 2-4, 1999 National Conference on Health Statistics sponsored by the National Center for Health Statistics/CDC. Travel and lodging are reimbursed for non-Federal conference participants whose papers are selected, and there will be an early 1999 deadline for abstracts. The conference will be held at the Omni Shoreham Hotel in Washington, D.C. For more information contact Barbara Butler (301-436-7122 Email BPB1@CDC.GOV) or Barbara Hetzler.

The disability sessions are organized by Paul Placek and described as follows:

(1) Measuring Dimensions of Disablement - This session covers the relationship between the health conditions of persons with disabilities and modifying environmental and personal factors. Included are studies of persons having impairments with or without major activity limitations, activity limitations with or without evident impairments, social participation limitations with or without im-

pairments, and/or secondary conditions resulting from some initial disability. New measurement instruments which capture these facets of disablement will be featured.

(2) Improving Disability Data: ICDH-2 Revision Activities in North America - The International Classification of Impairments, Disabilities and Handicaps (ICIDH) is undergoing a major international revision. This session seeks papers on results of systematic testing of the beta draft of ICDH-2 (the International Classification of Impairments, Activities and Participation: A Manual of Dimensions of Disablement and Functioning) and protocols for testing the Beta-2 version released by the World Health Organization in April 1999. Also solicited are papers on possible implementations of ICDH-2 in U.S. and Canadian disability programs. Finally, facets of presentation of a final version to the World Health Assembly in the year 2000 will be discussed.

The National Council on Disability (NCD) will conduct a public hearing in Albany, New York, on federal policy issues impacting people with psychiatric disabilities. The hearing is being held in conjunction with NCD's quarterly meeting, and will take place on Friday, November 20, 1998.

Dr. Ustun is pleased to announce a new staff member working on ICDH-2 revision in Geneva - Dr. Shekhar Saxena. Dr. Saxena represented WHO by phone hookup with the September 9 ISDS meeting, and will represent Dr. Ustun at the October 4-6 NACC meeting on ICDH-2 revision in Vail, Colorado. Contact information: Shekhar Saxena, Scientist, Unit of Epidemiology, Classification and Assessment, Division of Mental Health and Prevention of Substance Abuse, World Health Organization, Avenue Appia, Geneva 27, CH 1211, Switzerland, tel 41-22-791-3625 fax 41-22-791-4160, Email <saxenas@who.ch>.

Don Lollar announced that the call for comments on the draft national objectives for Healthy People 2010 was published in the FEDERAL REGISTER on September 8, 1998. The draft document can be accessed at the Web site: <<http://web.health.gov/healthypeople>>. Also, at the web site for HP 2010 is registration for the regional meetings. Don asks that you try to see if you or an advocate for healthy people with disabilities in a city close to you can register and attend the hearing. Particularly important is 1) making sure the chapter stays in, 2) including People with Disabilities as a subgroup under numerous of the other chapters, and 3) including the objective from "our" chapter which addressed "All patient encounter forms will include a summary of Activity Limitations, consistent with using the World Health Organization International Classification of Impairments, Disabilities, and Handicaps (ICIDH2) codes for all individuals receiving health care." Don is at <[DCL5@CDC.GOV](mailto:DCL5@CDC.GOV)>.

The National Institute on Disability and Rehabilitation Research is developing a new priority for a Center on Emergent Disabilities. The priority would be for funding next year and beyond. As part of the development process, NIDRR will conduct a focus group to explore issues and directions for research for the Center. NIDRR requests your suggestions for focus group participants and key readings. Please contact David Keer (email: [DAVID\\_KEER@ED.GOV](mailto:DAVID_KEER@ED.GOV)) to discuss your ideas.

President Clinton Announces New Medicaid Regulation.

On September 17, President Clinton announced that the Department of Health and Human Services has completed a new regulation that would give more than 20 million Medicaid beneficiaries in managed care plans the patient protections they deserve. The new regulation would bring the Medicaid program into compliance with the Patients' Bill of Rights. This proposed regulation would require managed care plans in all 50 states to provide needed patient protections to Medicaid beneficiaries, including access to specialists; anti-gag rules to ensure that health professionals can discuss all medical treatment options with their patients; access to providers for women's health services; access to emergency room services when and where the need arises; disclosure of clear, up-to-date information about benefits, plan operations, and protections; and a timely internal appeals process as well as an independent external appeals process.

Return-to-Work. On September 18, Vice President Al Gore announced that the Social Security Administration will award grants initially totaling \$4.4 million to nine states to develop innovative projects to assist adults with disabilities in their efforts to reenter the work force. These competitive grants are the first of a five-year, \$25 million program designed to provide coordinated approaches

to increase work opportunities for people with disabilities. The grants are the first under an Executive Order signed on March 13, 1998, by President Clinton that created the President's Task Force on Employment of Adults with Disabilities.

The United Nations Disability Program recently announced its accessible web page for persons with disabilities (<http://www.un.org/esa/socdev/disabled>). Among other things, the site contains copies of the World Programme of Action, the Standard Rules on Equalization of Opportunities for Persons with Disabilities, and information on the special rapporteur on disability of the Commission for Social Development.

NCD to Hold Third Annual Youth Leadership Development Conference. NCD has begun plans for its third annual Youth Leadership Development Conference. The conference, cosponsored by NCD and the Social Security Administration, will be held June 23-26, 1999, at the Radisson Plaza at Mark Center in Alexandria, Virginia. For information, contact Kathleen Blank at [kblank@ncd.gov](mailto:kblank@ncd.gov) or 202-272-2004.

#### REPORT OF OCTOBER 14, 1998, MEETING:

1. Paul Beatty (Email: [pbeatty@umich.edu](mailto:pbeatty@umich.edu)), Wendy Davis (email: [Wendy.L.Davis@census.gov](mailto:Wendy.L.Davis@census.gov)), Emilie Schmeidler (Email: [emilie@afb.net](mailto:emilie@afb.net)), and Corinne Kirchner (email: [corinne@afb.net](mailto:corinne@afb.net)) collaborated on the study, "Reading the Fine Print: Exploring Discrepancies in Print Reading Disability Estimates." Dr. Kirchner opened the group presentation by explaining that the impetus for this methodological study was the existence of an applied problem that needed to be solved. The National Library Service for the Blind and the Physically Handicapped, part of the Library of Congress, uses information on the prevalence of print reading disability estimates to support its requests for funding from Congress. Using data from the Health Interview Survey (HIS) and employing multiple regression calculations, the American Foundation for the Blind (AFB) developed national estimates of print disability. This estimate differed from findings of the Survey of Income and Program Participation (SIPP) which measured the same conceptual group. The National Library Service wanted these discrepancies resolved. Because a separate study was out of the question, it agreed to help finance a methodological analysis. Staff involved with the survey research laboratories of both HIS and the Census collaborated to explore these issues.

The National Library Service and the American Foundation for the Blind are part of the World Blind Union which consists of blindness consumer and advocacy groups and federal groups. NLS, AFB and several others in the North American/Caribbean region of the World Blind Union contributed funds to support this study for which \$75,000 was paid to the two survey labs; other costs were incurred by AFB.

According to the SIPP, 9.7 million Americans reported having a print reading difficulty in data collected in 1991/92. HIS data, involving an adult sample (1977) and an over-65 sample (1984) adjusted to 1990 population parameters, had 4.2 million Americans reporting a print reading difficulty.

Paul Beatty discussed the wording of the questions from the SIPP and HIS. The SIPP question reads, "Do you have difficulty seeing the words and letters in ordinary newspaper print even when wearing glasses or contact lenses if you usually wear them?" Respondents have the option of answering either yes or no to the question. And, if respondents answer yes, a follow-up question is posed, "Are you able to see the words and letters in ordinary newspaper print at all?"

In the HIS, the question begins with the statement, "The next few questions are about how well you can see, wearing your glasses or contact lenses if that is how you see best." The statement is followed by the question, "Can you see well enough to read newspaper print?" Respondents have the option of answering either yes or no to the question.

The surveys are similar, but the national estimates are very different. Are the findings accurate? Should researchers average the findings from the two surveys? Why does the discrepancy exist?

Paul Beatty noted differences between the statistics themselves. The 1991/1992 SIPP data

did not require the kinds of adjustments used with the 1977 and 1984 HIS data. Additionally, in the SIPP data, 40% of the respondents were proxies. There was a higher prevalence of print disability in the SIPP's proxy reports than in the self reports. The HIS strongly encouraged self reporting especially for the 1984 data.

Beatty discussed initial findings. Some non-trivial design and estimation differences were found, but they are probably insufficient to account for the full discrepancy. Additionally, although it was possible that real change had occurred over time, the researchers felt that age-adjustments should sharply reduce the gap.

Additional conceptual explanations were explored. The questions themselves were compared. In the SIPP, preceding questions address general disability. In the HIS, preceding questions address health and vision in particular. While glasses or contact lenses are referred to in the introductory statement, it is important to consider whether this subtlety is recognized by the time respondents answer the question related to print materials.

The wording of the SIPP and the HIS questions differ in emphasis. The SIPP asks whether respondents have difficulty seeing, while the HIS asks whether respondents can see well enough to read newspaper print. In essence, the answer categories are flip flopped. That is, a "yes" response to the SIPP question indicates difficulty reading print, whereas a "no" response indicates this on the HIS. Additionally, the focus of the surveys differ. The SIPP has questions on income, government participation and includes a module on health and disability, while the HIS covers health questions specifically. Presence of other questions about visual disability make a difference.

Interviews of subjects who fit the profile of possible respondents were conducted to ascertain whether they would answer the questions differently. The research design covered subjects with visual acuity ranges between 20/60 and 20/100 with best correction. A total of 30 respondents were interviewed in the metropolitan DC area. Three interviewing conditions were examined: context questions, conceptual differences, and the visual questions themselves. These were checked with cognitive probes. Answers were examined to learn what respondents meant and what explicit differences existed.

Beatty outlined the results of the study. The SIPP and HIS questions seem to address the same functional task: "see the words and letters," (SIPP) and "read" (HIS) are both interpreted as practical ability to read print. Subjects explanations of what terms meant did not seem to vary across interviewing conditions. Subjects did not see obvious differences between the questions.

The questions, however, do address different severity levels. The SIPP explores "difficulty seeing words and letters" while the HIS explores cannot "see well enough to read." Additionally, the SIPP follow-up question explores the inability to "see words and letters...at all."

Subjects frame of reference differs. Some people may barely require glasses, others may be unable to make out letters. Subjects tended to evaluate their visual abilities with glasses as the instructions asked them to. This represents a common sense frame of reference as glasses are perceived as everyday equipment. Even if they are required for reading, subjects considered themselves "able to read."

Subjects tended not to think about other magnification devices while answering. If magnification was needed, they tended to rate themselves unable to read. The only possible exception was that subjects' frame of reference might be influenced by an earlier HIS question about "use of magnifiers."

Both the SIPP and HIS questions have potential problems. The SIP has wordy questions and relies heavily on proxies while the HIS could benefit from more recent data from a general population sample. The central definition of "ability to read print" seem to be equivalent across questions, although the questions do suggest different severity levels. Even with small samples, the researchers observed qualitative and modest quantitative evidence that context is important. In-depth interviews suggested several key issues related to the discrepancy. Findings were helpful alone, but could also serve as a basis for larger experiments in the future.

Discussion: Mitch LaPlante suggested looking at the SIPP data over time and considering test/retest reliability. Bill Mann addressed the use of assistive devices. If researchers want to measure impairment, device use should be allowed. If researchers want to measure disability, device use should not be allowed. He cited the FIM scale which has a device use or non-use built into the scoring system.

The issue of how respondents with dyslexia are expected to respond to a question about reading was raised. Subjects interviewed for this study were all able to read. Subjects seemed to understand that the questions about reading and being able to see words and letters were getting at the same things which had to do with visual ability and not literacy.

Participants were interested in the variances and which of the different factors could be responsible for discrepancies. Contextual issues seem to influence answers. There is a need to make surveys more consistent.

Wendy Davis commented that it would be great to partition variances, but the study sample size was too small to do this. Researchers need to consider how context, such as the six questions preceding the HIS Questions having to do with visual impairments, influences respondents' answers. Additionally, the issue of magnification devices or other assistive services and their influence on responses cannot be answered definitively.

Kirchner explained that conceptually, researchers are leaning on questions on impairment, but what is needed is to get at a disability measure. She recommended building on Environmental issues. Literacy issues would be important to address. It would be useful to expand the scope of inquiry to those with learning disabilities and other impairments.

2) Nancy Mathiowetz (nmathiow@survey.umd.edu) discussed "Disability Research: A Methodologist's View." She explained that disability measurement is a very complex phenomena in part, due to different conceptual paradigms. Attempts to measure impairment, environmental constraints, naked [sic] ability and environmental impacts coupled with the reality that people may view themselves differently based on environmental accommodations adds complexity to disability research. As a survey methodologist, she raised concerns about the impact of essential survey conditions that may impact the validity and reliability of estimates of disability, for example, the wording of questions, the context of the questions, who is the reporter, and the mode and method of data collection (i.e., face to face vs. telephone, computer assisted interviewing vs. paper and pencil).

In the U.S., most disability measures used in ongoing federal surveys such as the SIPP and HIS have not been subjected to the types of cognitive testing that is used in many new surveys. It would be valuable to subject such survey instruments to these commonly accepted techniques, such as cognitive interviewing and behavior coding. In addition, enormously complex disability questions push to extremes subjects' working memory.

Mathiowetz referred to the National Council on Disability's recommendations regarding changes to Federal and State Disability Data Collection Instruments and efforts to measure disability or impairment in such surveys. For example, the Current Population Survey (CPS) could include employment statistics that provide information by impairment or disability status. Other Federal surveys need valid and reliable measures related to disability. Fundamental methodological research needs to address the measurement error properties related to various impairment or disability measures. In order for measures to be portable across surveys, we need to understand the impact of essential survey conditions on the validity and reliability of these measures.

Mathiowetz recommended the development of a short battery of items (between 2 and 10) and a 1-2 hour interview in which we understand how the 2 to 10 item screener psychometrically maps to the 1-2 hour interview. Once we have a set of screener items of interest, we can begin to address in a systematic way the measurement error properties of those measures under different essential survey conditions. It is important to look to well-designed experimental research. Perhaps that would help uncover why there are different estimates in surveys (such as was discussed in today's opening ISDS presentation).

Several federal agencies are involved and interested in collecting disability data and it is time to mount well-designed methodological surveys to collect information to inform those various data collection efforts as to the quality of the information.

Discussion: Michele Adler asked, "Specifically, what would you do to develop a short battery like HIS?" Mathiowetz replied that one could start from scratch or use questions we already have. This information could be fleshed out, starting to build a sound body of literature in peer reviewed journals.

Paula Franklin wondered, "what would happen when application is needed? What are we measuring? For what? For whom?" Mathiowetz commented that one set of measure won't work for all federal agencies, obviously their needs will differ. Questionnaire design work must focus on analytical objectives. Validity and reliability must be preserved. Validation needs to rely on issues beyond physical measurements (the traditional medical model). Reliability raises issues in the dynamic, complex process of disability.

Corinne Kirchner suggested that the ICIDH might provide the structure needed for methodological studies. Or, she asked, are there other structures to consider?

Mitch LaPlante raised the issue of how these kinds of survey questions are perceived. How is functioning seen and understood by people? How can we reduce this complexity to a few items? To serve various functions? It is important to look at function and the environment. The choice of rating scales is also a methodological issue. Going back to basics could prove to be very useful.

(3) Paul Placek (PJP2@CDC.GOV) presented "Overview of the Oct. 5-6, 1998 NACC Meeting on the ICIDH-2 Revision in Vail."

- o Forty-one people from five countries participated in this 5th Annual Meeting on the ICIDH.

- o On October 20-21, 1998 [sic], a WHO meeting took place in Geneva, Switzerland, where WHO gave the ICIDH Center Heads and Task Force Heads a progress report on beta testing. Janice Miller and Rune Simeonsson represented the North Americans.

- o The International Task Force on Environment has been funded at \$220,000/year for two years. The purpose is to add two digit environment codes to ICIDH-2.

- o WHO has extended Beta 1 testing until December 1998. Canada and France have successfully completed a full validation of the 1997 French translation and have used it to complete Beta-1 testing.

- o The Australian Collaborating Centre, with the assistance of an international reference group, is currently finalizing a plan to review the interconnectedness and structure of both the ICD-10 and the ICIDH-2 and to investigate any inconsistencies, overlaps and gaps. The objective of the study is to examine the extent to which the ICD-10 and draft ICIDH-2 classifications are harmonious, complementary and complete.

- o The Collaborating Centre in the Netherlands held a consensus meeting in Sept. 1998 with 50 Dutch and Flemish experts who discussed the Basic Questions, paying special attention to children's items. The Dutch plan to send two of their team members to Geneva to provide technical assistance during the Jan. - March revision of ICIDH-2/beta-2, to be released at the WHO ICIDH-2 meeting in the U.K.

- o A European consensus conference is planned for Oct. 30, 1998.

- o Jane Millar reported that the U.K. agreed to host the WHO meeting where the ICIDH-2 Beta-2 will be unveiled in early April 1999. The meeting will be in either Oxford or Cambridge.

- o Millar said that the U.K. would make recommendations for the inclusion of environmental factors, review and redraft the introduction to the ICIDH, and evaluate the WHO-DAS instrument.

- Special applications of the ICIDH-2 in the U.S.

- o Don Lollar of CDC/NCEH reported that 16 states were attempting to translate the ICIDH-2 into public health in practical ways working with the Behavioral Risk Factor Surveillance System (BRFSS).

- o Overtures have been made to HCFA encouraging the agency to look at collecting more

information involving activity limitation inclusion and participation.

- o CDC (Lollar) is also coordinating a new chapter in "Healthy People 2010." The chapter, "Disability and Secondary Conditions" uses the ICIDH as a conceptual framework for the objectives and goals.

- o LeeAnne Carrothers discussed the "ICIDH-2 and Risk: A Payor's Perspective Project" which involves specifying payor based criteria in and across health care systems.

- o Frederica Barrow of SSA highlighted the history of the Social Security Administration and its relationship to ICIDH-2. SSA is collaborating with NCEH and gave \$300,000 in FY'98 supplemental funding to 731 grantees Gray, Simeonsson, and Whiteneck. The focus is on disability among children and youth.

- o Leigh Anderson explained that the US Dept. of Veterans Affairs is taking a major look at ICIDH-2. The VA will start using the SF-36 with every veteran (all 9,000,000 - no sampling!) in the U.S.

- o Patrick Fougereyrollas and Luc Noreau of the Canadian Society for the ICIDH discussed their project of conceptual development and applications of new measurement tools. These environmental factors list may be used by the new Environmental Task Force.

- o Dr. Ustun, via telephone at the Vail meeting, said that the World Health Assembly will be presented with the ICIDH-2 Beta version for Year 2000 approval. He discussed plans for the ICIDH-2 fundraising meeting at the United Nations in New York City, in Feb. 1999, saying that three projects were proposed, and more were needed.

- o Adding to Paul Placek's remarks, Shekar Saxena of WHO Geneva explained that the ICIDH will be presented to the World Health Assembly in 2000. The translation process is going more slowly for developing countries than for developed countries. There will be a focus on developing countries in the next phase of this effort. The Task Force on Environment is looking at Environment and the model of disablement and how this could be conceptually and strategically useful. The goal is to move this process along. Regarding the fundraising meeting to take place next year, WHO welcomes proposals that will get potential funders interested. Shekar Saxena acknowledged NACC's contribution to ICIDH Revision process with this meeting.

## ANNOUNCEMENTS

The Mental Health Task Force on ICIDH-2 held a translation workshop. Its purpose was to focus on issues raised in translation. The language groups represented included English (U.K.), Turkish, and Tamel. Representatives of the Japanese and Spanish groups attended. Nigerian (Yoruda language) and Russian representatives were unable to attend. In response to the issues raised, next steps and deadlines were established. For more information on Task Force efforts, contact Cille Kennedy (email: ck71x@nih.gov).

Frederica Barrow of SSA and Don Lollar of CDC are pleased to announce that they have executed a \$300,000 FY 98 "SSA Cooperative Agreement with CDC for ICIDH-2 Research and Policy Applications to SSI Children and Young Adults." SSA funds will be assigned to Don Lollar's 731 grants with about \$100,000 each going to Drs. Gray, Whiteneck, and Simeonsson. Funding in future fiscal years is possible. For information about the project, contact Don Lollar at DCL5@CDC.GOV or Frederica H. Barrow, MSW, Social Insurance Specialist, Office of Policy, Social Security Administration, Altmeyer Bldg Room 128, 6401 Security Blvd., Baltimore, MD 21235, Tel 410-965-4731, Fax 410-597-0151, frederica.barrow@ssa.gov

## REPORT OF NOVEMBER 10, 1998, MEETING:

1. Dr. Susan Stoddard (email: disabilitydata@infouse.com) reported on InfoUse's "Chartbook on Work and Disability in the US, 1998." InfoUse is involved in the development of a series of



chartbooks which provide summaries of statistical information on disability. The chartbooks aim to make data accessible to a broad audience and reach more people than would in-depth reports.

It is a challenge to present and interpret disability statistics and to clarify the questions these data answer. It is an iterative process where InfoUse looks at data and identifies what questions are addressed. The chartbooks draw from a variety of statistical sources, applying policy questions to the available data.

The Chartbook on Work and Disability is written for a general audience. It includes a glossary of terms, a definition of sources and a bibliography. The Chartbook provides a broad overview of disability and work in the US and provides "sound bites," simple quick answers to complex questions that readers can delve into more thoroughly using resources cited. The goal is to provide current information, although it is recognized that there is a lag time between when data sets are released, analyzed and put into print. In addition to hard copy, the Chartbook is available on the Web and in Power Point format, which can be updated as new materials become available. Most disability data appear to be constant and are fairly similar from year to year.

Dr. Stoddard provided examples from Section 1 of the Chartbook. It covers the Prevalence of Work Disability. She showed a visual that highlighted the statement, "Almost 20% of people ages 15-64 report some level of disability." These data are from the SIPP and identify those reporting a non-severe disability as 10% of this population, while 8.7% report a severe disability within this age group. She also presented a visual showing that employment is lower for persons with a disability and much lower for those with a severe disability and a chart showing that more than two thirds of people with a work disability are not in the labor force. The Chartbook also covers factors related to work disability and identifies work-related disability benefits.

Dr. Stoddard pointed out disability data gaps that currently exist. Information is needed on 1) the work experience of people with disabilities, particularly those who work and do not self-identify; 2) jobs and worksites; 3) the impact of the ADA on job finding and job retention; 4) job skills and job retention; 5) success on the job for persons with disabilities; 6) accommodations; and 7) psychiatric disabilities and their relationship to work. Users can download Chartbook information from [www.infouse.com/disabilitydata/workdisability.html](http://www.infouse.com/disabilitydata/workdisability.html).

Dr. Stoddard also mentioned that a Chartbook on Women with Disabilities is currently in review.

David Keer commented that insurance companies will learn of the Chartbook's availability through an industry newsletter. Dr. Stoddard mentioned that a question was recently added to the InfoUse download procedure on its Web site to learn more about chartbook users. They include ILCs, students, and those seeking information for their personal use. A request has also come in to include Chartbook information in a textbook.

Karin Behe Bryant asked about how the Internet version of the Chartbook addresses the needs of individuals who have visual impairments. Dr. Stoddard explained that chart titles are included in the text version of materials. Data are explained in text, but descriptions of the types of charts used are not included. InfoUse is considering introducing small tables in future chartbooks as another means of presenting data.

Dr. Gerry Hendershot mentioned an upcoming CDC's ODH Conference on Women with Disabilities that JoAnn Thierry is organizing. Dr. Stoddard and staff were already aware of this project as Ms. Thierry is a reviewer of their upcoming chartbook. InfoUse will provide copies of the Chartbook on Women with Disabilities to conference participants.

Dr. Ustun congratulated InfoUse on its Chartbooks. He suggested a possible collaboration with WHO on an International Chartbook. He also suggested that for the broadest possible dissemination, the Chartbook in all its forms should be free.

2) Dr. Allen Meyers (Email: [meyers@bu.edu](mailto:meyers@bu.edu)) discussed the Oct. 8-9, 1998 CDC sponsored Conference on Health, Disability and Independent Living in the Graduate Public Health Curriculum. Thirty-five people attended this invitational meeting. Consensus findings from the conference will be summarized and circulated. It is clear that the Public Health field is taking a growing interest in the

lives of people with disabilities.

Prior to the meeting, a survey of all graduate schools and programs in public health was conducted regarding the study of disability within the graduate public health curriculum. Twenty-nine schools and programs responded out of a total of 35. Survey results were presented at the meeting.

The survey showed that treatment of disability is taking place within public health graduate programs and schools. However, a challenge is also evident, as a majority of public health schools and programs have no coverage of disability.

Dr. Mitch LaPlante asked Dr. Meyers to provide highlights from the survey and wondered about coverage of independent living. It turns out that 18 schools (62% of the respondents) have at least one course dealing with disability or have a dedicated course on disability. Schools provided their Syllabi, so it would be possible to identify coverage of independent living by examining these materials.

A salient question to consider is the relevance of disability studies in the public health curriculum. The schools may teach disability, but it is not clear from what perspective the instruction is provided. While the majority provide some study of disability, it is important to note that nearly 40% of the public health schools and programs provided no systematic coverage of disability. Those responding to the survey were deans or deans' delegates.

Dr. Paul Placek asked whether the survey checked if the ICIDH was part of the curriculum. Although it was not a survey question, there appears to be little coverage of the ICIDH in the schools and programs that responded. Dr. Hendershot wondered how many courses on disability contain statistical content? Dr. Meyers replied that disability content tends to be covered in gerontology or maternal and child health programs. Descriptive statistics are used, but not much happens beyond that. Syllabi, which are available through Dr. Meyers, can be examined for more specific information related to statistical content.

Dr. Paula Franklin discussed perspectives on disability including prevalence, an international focus, the relationship of acute and chronic conditions, and independent living. She expressed concern that these dimensions are not being studied. The complexity and richness of disability seemed untouched. She feared the focus was on disability within the context of illness alone, vs. part of a larger phenomena. She was glad, however, that the conference took place.

Dr. Meyers explained that schools of public health participated, as did the Association of Schools of Public Health. The Association is neither complacent nor defensive and will be meeting during the annual APHA meeting beginning November 15.

Dr. Yerker Andersson suggested that ICIDH definitions could play a big role in future public health instruction on disability. Dr. Meyers agreed.

Dr. David Gray asked if representatives from the IL movement attended the meeting. Both the Boston Center on Independent Living and the Center for Living and Working (the Wooster ILC) were represented. Dr. Gray asked about the top issues covered at the conference. Dr. Meyers commented that there was agreement that disability should be covered. The question or controversy was on how disability should be covered. Should dedicated courses on disability exist, or should disability be covered in matrix fashion? The overwhelming sentiment seemed to be to do both. This engendered discussion on logistics - how could courses in disability be sustained over time?

Issues under consideration involved what should be taught about disability, i.e., should the focus be disability studies or independent living in schools or programs of public health? A wide range of opinion exists. Academic freedom and philosophic standards may come into conflict. Consumers may have standards they want upheld, but those may differ from the academician's viewpoint. Dr. Meyers suggested that those interested in receiving conference proceedings and materials contact him at his email address listed above.

## ANNOUNCEMENTS

You are invited to participate in the Academic Symposium on Future Demographic Trends and their Potential Effects on Supplemental Security Income to be held December 3rd and 4th, 1998 at the Howard University School of Business Auditorium in Washington, DC. This event is a collaborative effort between the Howard University School of Social Work and the Social Security Administration's Office of Policy.

Lorayn Olson discussed Abt Associates work with NCHS on Random Digit Dial surveys. Abt is working to eliminate barriers to participation for individuals who are deaf or hard of hearing. Abt has not found a good information source on the number of TTY machines in homes. It is seeking to code TTY machines appropriately, not as fax machines. For more information on the project, email: [lorayn\\_olson@abtassoc.com](mailto:lorayn_olson@abtassoc.com)

Dr. Paul Placek has 200 ICIDH 1980 Red Books. He seeks to give them away. Please contact him at email: [pjp2@cdc.gov](mailto:pjp2@cdc.gov) for these free copies.

The American Public Health Association Annual Meeting took place on Nov. 15-19. The Disability Forum sponsored twenty-three sessions on disability, with over 100 presenters. All disability session were convened in the Convention Center. The Disability Forum, chaired by Paul Placek with David Keer as Program Chair, had a booth in the Convention Center Exhibits area and conducted its business meeting Monday night, November 16. It presented the Disability Achievement Award to Tony Young.

Bedhiran Ustun announced that WHO is being reorganized. The ICIDH is now in the Evidence and Information for Health Policy Section along with the ICD. It will form the basis for model health information systems.

A 17 Country, 19 Center Survey on WHO-DAS has been completed. The instrument now consists of 32 items. The reliability of the instrument is being tested.

Dr. Paul Placek announced that in addition to his oversight of the ICIDH, Dr. Bedirhan Ustun was recently appointed to oversee the ICD-10.

Dr. David Wasserman announced the December 1998 publication of "Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy," a book he has co-authored with Anita Silvers and Mary B. Wahowold. The authors, experts in disability issues, ethics and the law, address pressing issues in bioethics, including the prospect of genetic discrimination, heroic treatment of seriously impaired neonates, and how to assess the benefits and burdens of ending the segregation of people with disabilities. The authors bring leading theories of justice to bear on concerns of a wide variety of disciplines dealing with disability, including feminist, minority, and cultural studies and they do so within the context of the Americans with Disabilities Act. The book is available from Rowman and Littlefield Publishers, Inc., 1-800-462-6420 and costs \$54.00 in cloth and \$18.95 in paper.

### DISABILITY RIGHTS = HUMAN RIGHTS TAKE ADVANTAGE OF THE OPPORTUNITY TO INFLUENCE DISABILITY POLICY ON A GLOBAL LEVEL

The UC Berkeley School of Law is hosting a week long forum for the United Nations Consultative Expert Group on International Norms & Standards = Disability Law & Policy. Join us for the final session of these efforts for a Panel and Discussion on implementation of human rights for people with disabilities worldwide. The panel will include: representatives from the United Nations Consultative Expert Group on Disability Law & Policy, Human rights activists, & Local disability rights policy makers. Sponsored By: United Nations, UC School of Law, World Institute on Disability. DATE: December 11, 1998, TIME: 1:30-5:00pm. LOCATION: UC Berkeley, Boalt Hall/Goldberg Room.

NCHS's National Conference on Public Health Statistics will be held in Washington, DC, August 2-4, 1999. Two disability sessions are being organized by Paul Placek (email: [PJP2@CDC.GOV](mailto:PJP2@CDC.GOV)): Measuring Dimensions of Disablement and Improving Disability Data: ICIDH-2 Revision Activities in North America. Lighthouse International is sponsoring Vision '99, an Inter-

national Conference on Low Vision on July 12-16, 1999 at the Waldorf-Astoria Hotel in NYC. For more information, contact Lighthouse International (email: [vision99@lighthouse.org](mailto:vision99@lighthouse.org)).

The American Congress of Rehabilitation Medicine is holding its Annual Meeting entitled "Rehabilitation: Creating the State of the Art," on October 14-17, 1999 at the Radisson Twin Towers in Orlando, Florida. For more information call ACRM at (847) 375-4725 or see its Web page at <[www.acrm.org](http://www.acrm.org)>.

Mainstream Magazine and Ragged Edge (formerly Disability Rag) Magazine are holding a national meeting next May 21-23, 1999, in Louisville for disability activists and advocates concerned about "our national media problem: Disability issues - from our perspective - are not heard or discussed in the national media. Other minority groups are routinely asked their views on public issues. Not us. Why not?" Information from [circulation@ragged-edge-mag.com](mailto:circulation@ragged-edge-mag.com) on the conference "What we say ...What they hear: A beginning discussion" <[www.ragged-edge-mag.com](http://www.ragged-edge-mag.com)>.

#### REPORT OF DECEMBER 9, 1998, MEETING:

The theme for the session was "Progress under the ADA for Persons with Disabilities."

(1) Ruth Lusher (email: [Ruth.H.Lusher@usdoj.gov](mailto:Ruth.H.Lusher@usdoj.gov)), of the ADA Technical Assistance Program, Department of Justice, discussed DOJ's responsibilities under the ADA and its Technical Assistance Program. DOJ has developed a number of publications, including "A Guide to Disability Rights Laws," which provides a brief overview of different laws that ensure equal opportunity for people with disabilities and where to call for additional information and "ADA Information From the Department of Justice." For DOJ information on the ADA, access this Website at: <[www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm)>.

DOJ receives and processes complaints under Title II (State and Local Government Activities) and Title III (Public Accommodations Operated by Private Entities) and gathers statistics on its work. Although the agency is selective in opening complaints, its case load has grown dramatically. In FY '94, the total number of complaints that were open and under investigation by DOJ was 2,546. By FY '97, it had grown to 5,480 complaints.

Under Title III, DOJ offers an alternative to litigation through its mediation program. In FY '97, 298 complaints were offered the option of mediation. 180 complaints were actually referred to mediators and in 68 of them (89%), the mediation was successful. In 8 complaints (11%), mediation was not successful and 37 cases (21%) were referred but not mediated for various reasons. Presently, 200 cases are in mediation throughout the country. Originally, travel was not covered for the pro bono mediators and this sometimes influenced whether or not a case was mediated. This policy is changing. Additionally, it appears that funding may become available to pay for professional mediation of ADA complaints filed with the Department.

The ADA Technical Assistance Program toll free line (V: 800-514-0301, TT: 800-514-0383) receives increasing numbers of calls each year. In FY '95, 73,000 calls were received by the system and 7.5 million items were disseminated. By the end of FY '97, the number reached 163,000 and 8.1 million items were disseminated. DOJ receives many inquiries regarding whether certain entities are covered under the ADA, reflecting over 14% of the questions received. 20% of the callers receive referrals to other agencies. Approximately 16% of all calls involve requests for materials. Another 9-10% of the callers seek information on how to file a complaint. Inquiries also cover new construction/alteration standards (10.5%), auxiliary aids/effective communication (>2%), barrier removal (>3%), complaint status (>2%), program access (<4%), and policies (>5%). Other inquiries represent approximately 10% of the total.

(2) Arthur Lopez (email: [Arthur.Lopez@fta.dot.gov](mailto:Arthur.Lopez@fta.dot.gov)), Federal Transit Administration (FTA) Director of Civil Rights, Department of Transportation, discussed the FTA's responsibility for civil rights compliance and monitoring of Title II of the ADA and the Department of Transportation ADA regulations. DOT consists of almost ten distinct organizations which include, among others, the U.S. Coast Guard, the Federal Aviation Administration, the Federal Highway Administration, the Federal

Railroad Administration, the Federal Transit Administration, the Maritime Administration, and the National Highway Traffic Safety Administration. Each Administration has a presidentially appointed Administrator and separate chief counsels and civil rights directors. Prior to 1995, all of the ADA responsibility as it referred to transit, rested with program staff. In 1995, these responsibilities were shifted to FTA's Office of Civil Rights.

The FTA has a staff of 440 people with 10 regional offices. It oversees bus, paratransit services, and mass transit. Twenty-six staff members cover civil rights issues which include but are not limited to ADA. The FTA was an agency without a regulatory culture, but that has changed. Now it has an ADA Assistance Line (V: 1-888-446-4511; TDD/FIRS: 1-800-877-8339) and email assistance is available via: <ada.assistance@fta.dot.gov>.

The FTA has conducted outreach to the disability community. The main issue in ADA complaints stems from a lack of education and a problem in understanding rights. For instance, ADA Complementary paratransit services under ADA may differ from how paratransit was provided in the past pre-ADA. In order to qualify for ADA Complementary paratransit, people with disabilities who cannot because of disability ride on a fixed route bus are eligible for ADA Complementary paratransit services if they live or can be picked up within 3/4 of a mile on either side of the fixed route. Persons with disabilities must qualify and be certified to ride based on a transportation decision not a medical one. However, there may be paratransit services available to the well elderly or private systems that follow different eligibility criteria. Misinterpretations of the law occur.

Another possible bone of contention involves handicapped accessible seats. Although identified, people with disabilities are not required to receive priority. The ADA was based on access, not on priority. But if a place where a tie down is located is taken by a person without a disability, that individual cannot be made to move. It is not discrimination to cause the person with a disability who is waiting to board the bus to be made to wait, if the bus is full. The ADA requires accessibility, not priority or privilege.

Mr. Lopez cited the example of rail stations, and the ADA's emphasis on making key stations accessible. While 689 stations were designated as key stations, 350 stations had been granted regulatory time extensions or received voluntary compliance agreements resulting in milestones to make the stations accessible but had not fulfilled their obligations as promised. By 1996, FTA had established compliance reviews and had conducted 106 reviews at 32 of 33 properties. Agreements have been reached for 350 stations to come up to compliance by the year 2001.

David Gray asked whether a database exists on the number of accessible transportation units. Mr. Lopez replied that there is a National Transit Database, but the problem is that accessibility would be defined in terms of a low floor or a lift and would not cover the needs of cognitive or sensory impaired individuals. This creates a problem when talking about the accessibility of a bus that may have a lift or low floor but where the driver does not call the stops. To a person with a cognitive or visual disability, the vehicle is still not accessible.

Don Lollar wanted to know whether clear data sets exist to assess transportation compliance or if that information is collected on a site by site basis. There are rail accessibility data points which may cover rail stations. Clear data sets on paratransit, however, do not exist.

(3) Meryl Icove (email: MICOVE@fcc.gov), Director, Disabilities Issues Task Force, Federal Communications Commission, discussed her agency's efforts to focus on disability issues. FCC oversees telecommunications; its Disabilities Issues Task Force works to educate, inform, and promote awareness among people throughout the agency. It provides guidance on disability issues commission wide. Its WWW Homepage is: <www.fcc.gov/df>.

The Disabilities Issues Task Force conducts outreach on Commission activities to consumers and to advocates for the disabled. Ms. Icove discussed the 1996 Telecommunications Act which has two main provisions affecting persons with disabilities: the first is related to video accessibility while the second is Section 255.

The 1996 Telecommunications Act covers video accessibility (closed captioning and video

description). The FCC issued rules on closed captioning and issued a report on video description.

Section 255 of the Act requires manufacturers of telecommunications equipment and the providers of telecommunications services to make these accessible if such action is readily achievable. The Architectural and Transportation Barriers and Compliance Board was responsible for establishing guidelines for equipment. The FCC is putting rules in place for equipment and services which should be issued in February or March. It is clear that lots of competing interests exist and it must be done right.

The Disabilities Issues Task Force receives many telephone calls, emails and inquiries. It has begun tracking information. Other issues the Task Force is involved with include telecommunications relay service (a notice of proposed rulemaking is pending to make changes to TRS rules, speech to speech relay, universal service and billing collection and its impact on people with disabilities).

Bob Jaeger asked for an update on captioning on HDTV and for information on VHF broadcast bands and medical telemetry standards. FCC is working on HDTV and closed captioning. Rules address analog TV, but an NPRM will consider whether current industry standard should be turned into commission rules. More advanced captioning is possible on HDTV and the agency is focusing on this issue.

While medical telemetry is important, Ms. Icové did not have much familiarity with the issue. She did note that shared frequencies have certainly come up as an FCC issue related to assistive listening devices and protecting consumer needs.

Ms. Icové was asked if access to the WWW is within the purview of the FCC. She replied that it is DOJ's responsibility. It was mentioned that NIDRR and the National Science Foundation (NSF) are co-funding an effort on Web accessibility.

(4) Sherry Powers, Attorney Advisor, Office of General Counsel, Equal Employment Opportunity Commission, tel. (202) 663-4765 opened her presentation by directing the audience to the EEOC Website: <http://www.eeoc.gov> for enforcement statistics, and the EEOC ADA litigation docket, which includes the docket of active and resolved ADA lawsuits and information on specific cases. She discussed cumulative EEOC statistics that have been recorded since the ADA came into effect.

Of the 106,479 ADA charges that have been administratively closed, the following impairments are the largest categories presented. 21.4% are listed as other (a category EEOC plans to rework so that it provides more information), 16.9% involve back impairments, 10.6% are neurological, 9.4% involve impairments to the extremities, 7.7% represent those regarded as having a disability, 8.8% have depression, and 4.2% cover other mental illnesses (excluding schizophrenia and manic depression (1.5%)). Heart impairments constitute 4%; diabetes (3.5%), hearing (2.8%), visual impairments (2.5%) cancer (2.4%), asthma (1.7%) and HIV (1.7%) have also been identified in the charges closed. Drug problems, allergies, cumulative trauma syndrome, chemical sensitivities, respiratory impairments and speech impairments each make up 1% or less of total charges administratively closed. 13.8% of the charges have had merit resolutions meaning that the charges were settled prior to in Court litigation and 34.8% of the charges underwent administrative closure.

As of March 31, 1998, EEOC filed 278 lawsuits under the ADA. At that time, there were 98 active ADA cases on EEOC's Trial Docket. The cases that have made their way to U.S. District Court cover a variety of impairments. A sampling include: 14.7% are identified as "other," 13.7% involve HIV/AIDS, 12.9% involve back impairments, 6.8% involve hearing impairments, 6.5% involve cancer and 5.4%, diabetes, and 4% involve emotional, psychiatric or psychological impairments. The roster includes other conditions. Approximately 95% of the lawsuits resulted in monetary or injunctive relief. EEOC has only lost about 5% of the ADA cases resolved to date.

The Courts have tended to develop restrictive definitions of who is disabled under the law. Ms. Powers cited a recent Supreme Court case, *Braddon v. Abbott* (Westlaw 332958 US) where the definition of disability was discussed at length. The Supreme Court found that asymptomatic HIV is a disability. The Court reasoned that HIV's effect on the human body causes immediate and serious internal damage that constitutes an impairment from the start. It decided that a major life activity,

reproduction, was affected by HIV, since the risk of passing the virus from a female such as the plaintiff to a male partner was 20% and the risk of passing the virus to her unborn child was 25%.

The floor was opened to discussion. It was noted by a member of the audience that the federal government has approximately 55 definitions of disability. One audience member asked if the number of complaints were compared to specific impairments in the general population, would it indicate which impairment groups would be most likely to be discriminated against? Ms. Powers suggested that litigation numbers based on disability may not be indicative of discrimination levels. Whether the EEOC files a lawsuit depends on many factors that have no connection to the distribution of impairments in the general population. There was a suggestion that ICIDH definitions and categories might assist in developing uniform definitions of disability.

Ms. Powers commented that once the data on impairments are refined, this information should appear on the EEOC Web site. For more information, contact Ms. Powers by telephone at (202) 663 -4765.

## ANNOUNCEMENTS

1998-99 APHA DISABILITY FORUM OFFICERS. Rene Jahiel attended the ISDS meeting to introduce himself and name the following officers: CHAIRPERSON Rene Jahiel, M.D., JAHIEL@NSO2.UCHC.EDU; PAST CHAIR AND DELEGATE TO THE GOVERNING COUNCIL Paul J. Placek, Ph.D., PJP2@CDC.GOV; CHAIR-ELECT David W. Keer, M.A., DAVID\_KEER@ED.GOV; SECRETARY/TREASURER Elaine Jurkowski, M.S.W., Ph.D., ETJURKOW@SIU.EDU; POLICY CHAIR Bob Griss, bgrissdh@aol.com; COMMUNICATIONS CHAIR Thomas E. Stripling, TOMS@PVA.ORG; and PROGRAM CHAIR JoAnn M. Thierry, CDC/NCEH/OD, Chamblee 101 - Rm. 309, Mailstop F-29, Atlanta, GA 30341-3724 Tel 770-488-7097 Fax 770-488-7075 Email JXT4@CDC.GOV.

The American Association on Health and Disability is newly formed, and comprised of the American Disability Prevention and Wellness Association and the Association of State and Territorial Disability Prevention Programs. The New Officers are: Mike Marge, President; Tom Seekins, President Elect; Don Wagner, First VP; Glen White, Second VP; Donna Scandlin Secretary; and Roberta Carlin Treasurer. Newsletter Editor is Tom Seekins, RTC Rural, 52 Corbin Hall, University of Montana, Missoula, MT 59812 <Ruraldoc@selway.umt.edu>.

Healthy People with Disabilities 2010, the Nation's blueprint for promoting health, will have a separate section on disability, and to learn more, log on to: <<http://web.health.gov/healthypeople2010Draft/index.htm>>.

The Society for Disability Studies office is being moved at this time to the University of Illinois at Chicago. If you would like further information about SDS see the SDS website at <[www.wipd.com/sds](http://www.wipd.com/sds)> or <[members.tripod.com/~disabilitystudies](http://members.tripod.com/~disabilitystudies)>.

The International Federation on Ageing's Fourth Global Conference on Ageing, will be held in Montreal, September 4-9, 1999. Fourth Global Conference on Ageing Secretariat - JPD/L 555 Peel, Suite 500 Montreal, Quebec, Canada H3A 3L8 Telephone: (514) 287-1070 Fax: (514) 287-1248 E-mail: [jpd1@jpd1.com](mailto:jpd1@jpd1.com) Conference Web site: <<http://www.ifa-fiv.org>>.

The Salzburg Seminar Session 369, Salzburg, Austria, July 10 - 17, 1999; The Challenges of an Aging Society: The Intergenerational Contract. Application deadline: April 10, 1999; Admissions Office, Salzburg Seminar, Box 129, A-5010 Salzburg, Austria; Telephone +43 (662) 839830, Fax +43 (662) 8398366, Email <[admissions@salsem.ac.at](mailto:admissions@salsem.ac.at)>, URL: <<http://www.salsem.ac.at>>.

Howard Bradley [SMTP: [howard.l.bradley@ssa.gov](mailto:howard.l.bradley@ssa.gov)] reports that the January 27-28, 1999, NASI conference will be held at the National Press Club. The theme of the conference will be: Social Security and Medicare: Individual vs. Collective Risk and Responsibility. Co chairs will be: Sheila Burke, Eric Knigson and Uwe Reinhardt.

PLEASE MARK YOUR CALENDAR WITH OUR 1999 ISDS MEETING DATES, ALL

ON THE SECOND WEDNESDAY FROM 1:30 pm - 3:00 pm EST or EDT: April 14, May 12, June 9, July 14, August 11, September 8, October 13, November 10, and December 8.

**WHERE: SEVEN LOCATIONS**

1. Hubert H. Humphrey Bldg. Rm. 317B. HHH is at 200 Independence Avenue, SW in DC and the nearest Metro Stop is Federal Center SW.
2. Baltimore SSA meets in Link 1-M-28A - anchor Paula Franklin.
3. Hyattsville/NCHS Meets in Presidential Bldg. Rm. 10-66.
4. Research Triangle Park, North Carolina (12 Davis).
5. University of California at San Francisco.
6. Washington University, St. Louis, MO.
7. World Health Organization, Geneva, Switzerland.

NOTE: Access to the first five Federal Buildings listed above is very restricted so if you do not have a Federal ID and wish to attend, contact a Federal employee in that building to escort you in.

**CALL IN AND PARTICIPATE IN THE ISDS MEETING! IF YOU ARE NOT NEAR AN ENVISION SITE AND WOULD LIKE TO PARTICIPATE IN THIS ISDS MEETING BY PHONE, JOIN US BY USING THE CDC PHONE BRIDGE: FEDERAL PARTICIPANTS CALL: 404-639-3277; NON-FEDERAL PARTICIPANTS CALL: 1-800-311-3437; CONFERENCE NAME: Disability Statistics; CONFERENCE CODE: 959605; TIME: 1:30 - 3:00 p.m. EST (START DIALING AT 1:20), PARTICIPANTS LIMITED TO 20.** If you have a problem during your conference, you may press \*0 at anytime to signal the attendant. If you have questions about the technical operations of the teleconference equipment please call 404-639-7550. The NCHS Hyattsville Envision site will also call in and link the callers to the Envision. Callers will be able to speak to each other, and if the Hyattsville site is unmuted those callers can speak to persons at all eight Envision sites.